CHAPTER V. CASE REVIEW METHODS

This chapter describes the process used in the case-by-case review of infant deaths. The goal of this review was to identify factors which contributed to infant deaths in King County, especially those factors which could be modified. Subsequent chapters report on the findings of the Review.

CASE IDENTIFICATION

The Review's identification of cases of infant death began in 1992 and is still ongoing. This report includes cases of infants who died between 1992 and 1994, as the review of some cases from 1995 is still ongoing.

Eligibility for the Review was limited to live born infants who died before their first birthday and whose parents were residents of King County at the time of their child's birth and death. Only King County residents were included because our aim was to describe factors specific to King County. After the first fourteen months of the Review, infants with congenital anomalies (birth defects) were excluded because few contributing factors associated with these deaths could be changed. The Review did not consider cases where homicide was the suspected cause of death because homicides comprise a very small number of King County infant deaths, averaging of 1.4 annually, and because staff working on the review could not be involved in the lengthy litigation and potential legal issues surrounding these cases.

Selection of eligible cases was made after reviewing the death certificates of all infants who died in King County and in neighboring Pierce and Snohomish counties. These were compared to death certificates collected by the Washington State Center for Health Statistics for King County infant deaths to assure complete ascertainment of all death records.

DATA SOURCES

Data were gathered from vital records (birth and death certificates), maternal and infant medical records, medical examiner reports, autopsies, transport records, and information from Child Protective Services and other social service agencies. Whenever possible, a voluntary interview with the mother or the caregiver of the infant was conducted to provide further information.

VITAL RECORDS

Birth certificates in Washington State provide generally accurate reporting of maternal and infant race, maternal age, marital status, indirect measures of socioeconomic class such as education and payer for medical insurance (Medicaid and other), gestational age, birthweight, initiation of prenatal care, smoking, and birth complications.[1] Several studies have demonstrated that the Washington State vital records contain valid data, with a very small error rate (see Appendix A under "The Validity of Vital Records Data" for more information). The major limitation of vital records is their lack of information on delivery of health and human services, social support, stress, substance abuse and poverty. Therefore, data on these factors were mainly captured through record abstraction and interviews.

RECORD ABSTRACTION

Maternal and infant medical records from hospitals and outpatient providers delivering prenatal, labor and delivery, and post-natal infant care were abstracted, using a standardized form. All records were abstracted by a specially trained physician or public health nurse. Information gathered from maternal

medical records included obstetrical history, medical conditions during the mother's pregnancy, diagnostic procedures, timing and amount of prenatal care, and medical conditions and complications during labor and delivery. From infant records we collected information on the infant's health status at the time of delivery and the subsequent course, timing and content of well-child visits and medical care for all illnesses. Medical examiner reports, autopsies, transport records, information from Child Protective Services, and social services records were also included.

INTERVIEW

The purpose of the interview was twofold: First, it gathered information from the mother or infant's primary caregiver about the mother's pregnancy, the infant's health, and the circumstances of the infant's death. Second, it provided grief assessment, support, and referral to community resources. Realizing the sensitive nature of the visit and the fragility of families following the death of a child, contacts were delayed until six weeks following each infant's death. A letter was then sent to the mother or primary caregiver, expressing sympathy over the death of the baby, explaining the Review and asking for an interview. The letter was then followed by telephone contacts by public health nurses to set an appointment time for an interview. If the nurses were unable to contact the family by telephone after several attempts spread over several weeks, or if the family had no telephone number, they then made an informal home visit to deliver the letter and encourage an interview. A $25 gift certificate was offered to those participating in the interview in recognition of their participation.

The interview, averaging about two and one half hours in length, gathered information on the social and health circumstances of the family and demographic information such as income, employment and education. Additional data were gathered on reproductive history, family composition, whether the deceased child had been planned, prenatal care, stress, available social support, and behavioral risk factors such as smoking, alcohol and drug use. Information was also collected on several aspects of delivery and post-partum care, including knowledge of different care needs, satisfaction, problems, and payment. Each family told their story of their child's death and their accounts were recorded.

The public health nurses paid careful attention to the psychological and emotional needs of family members during the interview. They assessed each individual's grieving process and offered support. This was an important part of the visit. The nurses took this opportunity to share information concerning community resources for grieving families as well as sources of help for other identified needs. Referrals were made when appropriate.

As noted, we revised the data collection process in the beginning of 1993, because we had found that infant deaths due to congenital anomalies or to extreme prematurity revealed few modifiable contributing factors. These cases were referred to field-based public health nurses for a home visit and a screening interview. The nurses visited the mother or caregiver of the deceased infant and offered grief support and referrals to various services as deemed necessary, in addition to a brief screening interview. The interview included questions about the mother's socio-demographic characteristics, prenatal care issues, past pregnancy history, behavioral risks, stress, the amount of social support that the mother had during pregnancy, circumstances surrounding the infant's death, medical advice received during pregnancy and child birth, and services offered to her or her infant after birth and after the infant's death. The nurse also assessed the home environment (e.g., whether house or apartment, number of bedrooms, urban/rural location, number of household members and who they are, number of children, household members who smoked, and cleanliness). Data collected by the field nurses were subsequently screened by project staff and a more detailed review, including medical record abstraction and full expert panel

review, was performed for any cases with the potential of revealing new or unique modifiable contributing factors.

While much important information was available from these sources, they did not necessarily provide a complete description of the events leading to the infant's death. For example, medical records may not have recorded all the observations and actions of providers. The providers involved with the case may have had unique and important insights into the case that remained unknown to the Review committees.

CASE REVIEW PROCESS

The process used for reviewing cases is summarized in figure 5.1. The Review staff prepared a written summary of each case from all data sources which was then reviewed by one of two expert panels. The more complex cases were reviewed by the **Technical Review Committee (TRC)** consisting of:

- Obstetricians
- Pediatricians
- Family practice physicians
- Midwife
- Genetic counselor
- Epidemiologists
- Associate Medical Examiner
- Social workers
- Hospital and public health nurses
- Representative of Child Protective Services (CPS).

The less complicated cases were reviewed by the **Brief Review Committee (BRC)**, a smaller panel composed of:

- Obstetrician
- Family practice physician
- Pediatrician
- Nurses
- Epidemiologists

In each case, the committees reached consensus on the cause of death and then identified factors which contributed to the death. A factor was considered a **contributing factor** if, in the opinion of the panel, it was reasonably likely to have been part of a causal pathway leading to the death of the infant. The determination of whether a factor was contributing was reached on a case-by-case basis. The same factor may have been judged to have contributed to death in one case because of the context in which it occurred but not to have contributed in another.[a]

[a] For example, a mother went into preterm labor and laboratory tests detected use of cocaine at the time of delivery. The committee deemed her drug use to be contributory to fetal distress and premature delivery. However, in another case, the infant of a mother who admitted to cocaine use prior to her pregnancy diagnosis was born prematurely. The newborn died of a respiratory infection acquired while hospitalized for prematurity. The TRC decided that the infant's lung problems, caused by prematurity, and the acquired infection both contributed to the infant's death. There was insufficient evidence in this case to implicate drug use as contributing to the death.

Contributing factors were rated for their *importance* in causing the infant's death. In addition, the committees assessed whether the factor was of high, moderate or low *modifiability* through health, social service or other interventions. Determination of importance and modifiability was also case-specific. Multiple factors were identified in many cases. Cases where the cause of death was unknown were not assigned contributing factors. Because the cause of SIDS is unknown, the committees could not assign contributing factors to SIDS cases.

In addition to describing the contributing factors, the committees identified conditions (which we called "**associated factors**") that had the potential to adversely affect the health of pregnant women and infants, although insufficient information was available to determine whether they contributed to the specific death under review. While the range of associated factors was broad, many were social and economic issues. The latter are discussed in Chapter VII.

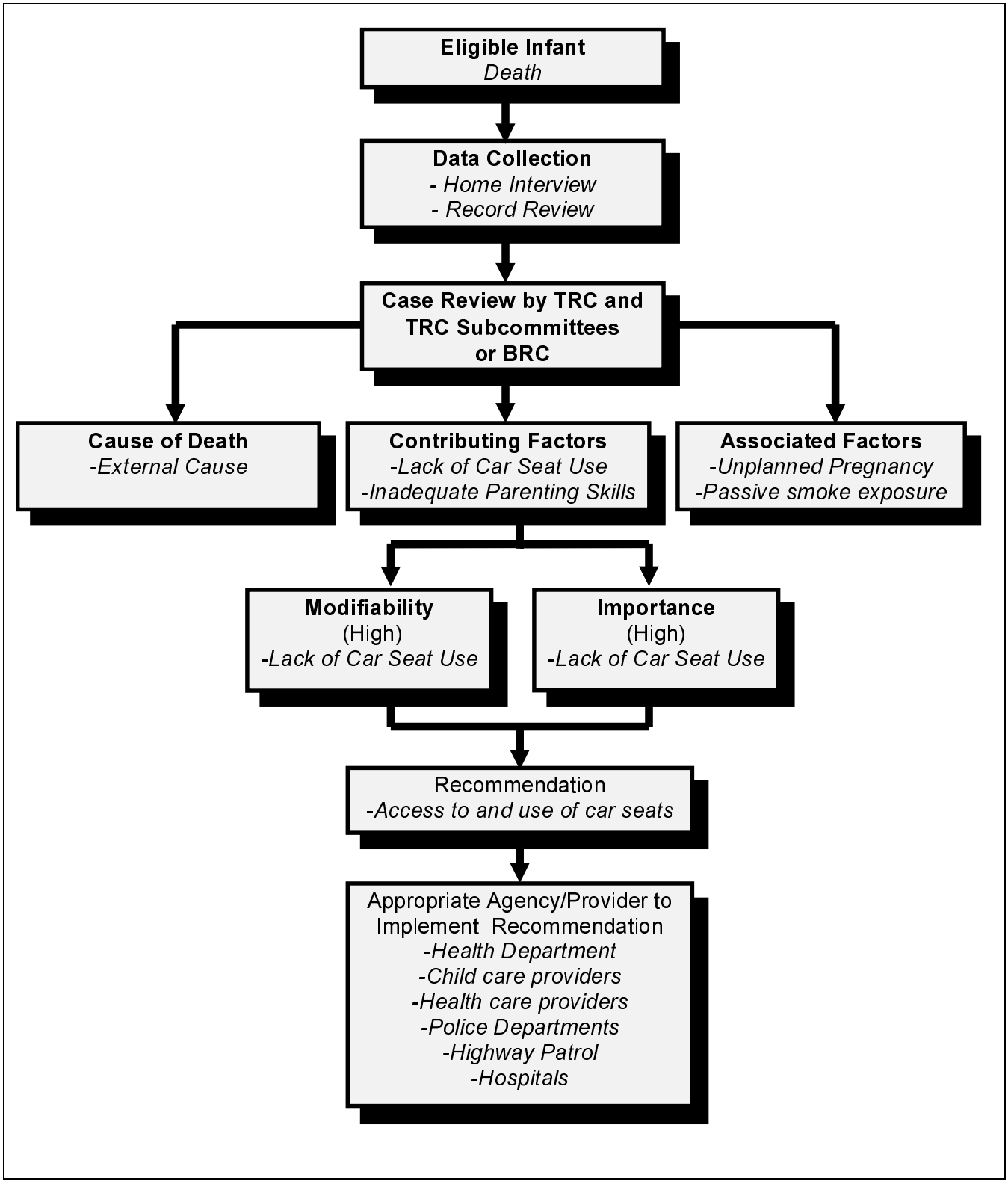
The assessment of some groups of factors required special expertise and the review committees referred them to specialized subcommittees. Three areas were initially identified for subcommittee review:

- **Obstetrical Subcommittee** - reviewed cases with factors related to pregnancy, labor and delivery, and those involving the newborn immediately after birth.
- **SIDS and Sleep Safety Subcommittee** - reviewed cases where sleep conditions and sleep safety were of interest. This included both SIDS cases and infants who died of accidental suffocation while sleeping.
- **Inadequate Support Services Subcommittee** - reviewed cases with factors related to community and ancillary services for pregnant women and infants.

After careful review of the case groupings, recommendations for interventions were made. Reports from the Support Services and Obstetrical sub-committees are included in Chapters VIII and IX of this report. The findings of the SIDS and Sleep subcommittee will be presented in a future report. Additional subcommittees will consider cases of prematurity, lack of prenatal care, substance abuse, and management of infant health problems.

Figure 5.1 illustrates the process of assigning causes and factors related to infant death:

FIGURE 5.1
PROCESS FOR ASSIGNING CAUSE OF DEATH, AND FACTORS CONTRIBUTING TO DEATH[a]



[a] Text in italics is offered as an example

HUMAN SUBJECTS PROTECTION

The protocols of this project were reviewed and approved by the University of Washington Institutional Review Board.

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[1] Frost F, Starzyk P, George S, et al.: Birth complication reporting: The effect of birth certificate design. Am J Public Health 1984; 74:505-506.